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Representações de pacientes oncológicos sobre o tratamento de quimioterapia antineoplásica*

Oncologic patients representations about the antineoplastic chemotherapy treatment

Pacientes oncológicos representación de la quimioterapia tratamientos antineoplásicos

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ABSTRACT

Objective: To understand and identify the representations of cancer patients on antineoplastic chemotherapy treatment and nursing care. **Methods:** Descriptive, qualitative research, analyzed regarding the phenomena of the Theory of Social Representations and content analysis technique proposed by Bardin, held from June 24 to July 31, 2015, with 22 patients diagnosed with cancer and under chemotherapy treatment. **Results:** After analysis of the collected material were consolidated four thematic units, named: “Chemotherapy: the chance of cure”, “Nursing care in chemotherapy”, “The daily life of interpersonal relationships during chemotherapy treatment” and “The difficulties during the chemotherapy”. **Conclusion:** Through research, you can see the importance of health education for the understanding of patients and their families about cancer and its treatment.

Descriptors: Nursing; Chemotherapy; Social Psychology.

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RESUMO

Objetivo: Compreender e identificar as representações de pacientes oncológicos sobre o tratamento de quimioterapia antineoplásica e o cuidado de enfermagem. **Métodos:** Pesquisa descritiva, qualitativa, analisada à luz dos fenômenos da teoria das representações sociais e da técnica de análise de conteúdo proposta por Bardin, realizada no período de 24 de junho a 31 de julho de 2015, com 22 pacientes com diagnóstico de câncer e em tratamento de quimioterapia. **Resultados:** Após análise do material colhido, foram consolidadas quatro unidades temáticas. Assim denominadas: “quimioterapia a chance de cura”, “o cuidado de enfermagem na quimioterapia”, “o cotidiano das relações interpessoais durante o tratamento de quimioterapia” e “as dificuldades durante o tratamento de quimioterapia”. **Conclusão:** Através da pesquisa, pode-se observar a importância da educação em saúde para o entendimento dos pacientes e de seus familiares sobre o câncer e seu tratamento.

Descritores: Enfermagem, Quimioterapia, Psicologia social.

RESUMEN

Objetivo: Conocer e identificar las representaciones de pacientes oncológicos que reciben quimioterapia, tratamientos antineoplásicos y atención de enfermería. **Métodos:** Investigación descriptiva, cualitativa, analizada a la luz de los fenómenos de la teoría de las representaciones sociales y la técnica de análisis de contenido propuesta por Bardin, celebrada del 24 de junio a la el 31 de julio de 2015, con 22 pacientes diagnosticados con cáncer y el tratamiento quimioterapia. **Resultados:** Tras el análisis del material recogido se consolidaron tres unidades temáticas. La llamada: “Quimioterapia las probabilidades de curación”, “cuidados de enfermería en la quimioterapia”, “las relaciones interpersonales diarias durante el tratamiento de quimioterapia” y “dificultades durante el tratamiento de quimioterapia”. **Conclusión:** A través de la investigación, se puede ver la importancia de la educación sanitaria para la comprensión de los pacientes y sus familias sobre el cáncer y su tratamiento.

Descriptores: Enfermería; Quimioterapia; Psicología Social.

INTRODUCTION

Over the centuries, medicine has become increasingly advanced in obtaining an early diagnosis and treatment of cancer, but this disease, among many others, is still feared and regarded as a synonym of death in the midst of society. This ideology is maintained through the various popular knowledge about cancer, myths, and taboos, which are still strongly anchored to the imaginary of people.¹

In Brazil, the estimate for the year 2014, as well as for the year 2015, points to the occurrence of approximately 576 thousand new cases of cancer, including cases of non-melanoma skin cancer, which reinforces the magnitude of cancer problem in this country.²

The treatment is performed by the following modalities: surgical, chemotherapeutic, radiotherapeutic and biotherapeutic, being surgery the first treatment and choice for several types of cancers. Regarding chemotherapy, it is classified according to its purpose as adjuvant, neoadjuvant, primary, palliative, mono-chemotherapy and polychemotherapy.³

Chemotherapy is a systemic treatment based on chemical compounds that are administered uninterruptedly or in an interval manner according to the treatment schedule, being called anti-neoplastic or anti-cancer chemotherapy when used to promote the cure of cancer, considering that it acts at the cellular level, focusing on reproduction.⁴

Despite the great benefits in the fight against cancer, chemotherapy also tends to cause adverse effects, which are often considered aggressive and can lead to changes in self-esteem, in the functional loss of the patient, so the nursing team has to be qualified in face of the characteristics of the mechanisms of action of drugs used and their possible adverse reactions.⁵⁻⁶

In this context, this research aims to understand and identify the representations of oncology patients about the treatment of antineoplastic chemotherapy and nursing care, being this delimited representation as the object of study. Social representations are constituted through a system of values, ideas, and practices, with a dual function in which an order is first established that enables people to orient themselves in their material and social world to be able to control it, and later through communication among the members of a community, to unambiguously name and classify the various aspects of their world and their individual and social history, creating together new ideologies.⁷

Thus, it is fundamental to study the subjectivities involved in the process of getting sick with cancer, since the treatment, even being one of the most advanced, may be ineffective and/or abandoned if the patient has not received information about the disease and its treatment. In this context, the Social Representations (SR) has the function of interpreting the reality that surrounds and guides the individual in their attitudes and those of the group in which they belong.³

It is emphasized that cancer and chemotherapy are a psychosocial object when it is part of the individual's cognitive and sharing with his or her group. For this reason, health, like the disease, is a legitimate object for the use of SR, since it is present in the daily life of various groups that make up society. In this way, the importance of revealing the social representations (SR) of clients affected by cancer on chemotherapy, since only through this knowledge will it be possible to implement health care that values the quality of life of the patient being cared for.

Regarding those facts, it is also evident the need for humanized health professionals, especially the nursing team, given that they are the largest category and are closest to the patient, to assist and promote the patient's strength to face the disease and its treatment, so that the patient feels supported, since like any serious illness, cancer confronts the patient and his family with the risk of imminent death, causing deeply changes their lives.

Thus, knowing the social representations of oncology patients about chemotherapy treatment and nursing care will greatly contribute to the implementation of nursing care, in which a quality care can be offered based on the real needs

of patients and close existing gaps in their mental. Once these representations are unveiled, much can be thought of and improved in the practice of health care.

It is understood that, due to the fact that this is a descriptive research, a design will be developed about the representations of oncology patients on the treatment of antineoplastic chemotherapy and on nursing care, propitiating the elaboration of new assistance strategies in the oncological context and that will fit the reality that is about to be formed.

Regarding the research, this study will contribute to the practice of nursing in oncology, due to the information it will offer about oncological patients under chemotherapy treatment and how to listen to the complaints, doubts, and wishes, making possible to offer better health assistance.

METHODS

This is a qualitative descriptive study, which was performed at the chemotherapy clinic of the João de Barros Barreto University Hospital (HJBB), in the city of Belém, state of Pará, located at Rua dos Mundurucus, number 4487, Guamá, Belém/PA, from June 24 to July 31, 2015. In this research, the cognitive universe of cancer patients on chemotherapy treatment and nursing care was analyzed regarding the phenomena of Social Representations Theory.

The subjects of the study were 22 patients diagnosed with cancer in the antineoplastic chemotherapy treatment at HJBB chemotherapy service. Were included in the study patients with a positive histopathological condition for cancer, in good cognitive status and with no difficulties to verbalize, aged over 18 years, undergoing antineoplastic chemotherapy for at least one month, who voluntarily agreed to participate in the study, signed the Term of Informed Consent (TIC). Patients who were not diagnosed with cancer, with cognitive and speech disorders, under the age of 18 years, who had not been receiving antineoplastic chemotherapy for at least one month, and patients who did not agree to sign the EHIC were excluded from the study.

The data collection was done from a semi-structured interview, which was recorded in an office inside the chemotherapy center, where the nursing consultation was usually performed. The interview was fully transcribed in a Word file and returned to the subjects for confirmation of their statements.

For the material analysis, the technique of content analysis proposed by Bardin was used, which presupposes some steps: 1st - Pre-analysis: Development of the preparatory operations for the analysis, the process of choosing the documents or definition of the corpus of analysis; 2nd - Material exploitation or codification: the transformation of raw data, which will allow an accurate description of the relevant characteristics of the content expressed in the text; and 3rd - Treatment of the results: Inference and revelation, interpretation of the information provided by the analysis,

through simple or more complex quantifications, such as factorial analysis, allowing to present the data.

The units were created, aggregated and subjected to an exploration to better understand the research object through contents considered more significant in each text, in order to consolidate in four units, named: "Chemotherapy: the chance of cure", "Nursing care in chemotherapy", "The daily interpersonal relations during the treatment of chemotherapy" and "Difficulties during the treatment of chemotherapy".

In order to carry out the research, the ethical norms established by Resolution No 466/12 of the National Health Council were fulfilled, which regulates research standards involving human beings, incorporating, from the point of view of individuals and collectives, the bioethics and aims to ensure the rights and duties that concern the research participants, the scientific community and the State.⁹ The research was accepted by the Committee on Ethics in Research with Human Beings of the Hospital Universitário João de Barros Barreto, having as Opinion No 1,119. 886.

RESULTS AND DISCUSSION

The results provided and discussed are based on the discourse of 22 oncology patients on chemotherapy, eleven (50%) males, and eleven (50%) females, eleven (50%) married or in a stable union, thirteen (59.09%) are Catholics. With regard to the education level, eight (36.36%) had incomplete primary education and eight (36.36%) had completed secondary education. The age range varied from 30 to 78 years old, with eleven (50%) patients in the age range of 60 to 78 years old.

Unit 1: Chemotherapy: the chance of cure

When talking to individuals in treatment about any therapy used against cancer, it is possible to see the desire to be cured and get rid of the disease. Cancer, despite being a chronic degenerative pathology, as well as diabetes mellitus and systemic arterial hypertension, has its meaning naturally associated with pain and death. Thus chemotherapy is not only a cure for these patients but the possibility of not dying.^{10-1,5}

According to the testimonies of sixteen (72.8%) interviewed, the institution of chemotherapy as a treatment for cancer brought them the hope of achieving a cure. This feeling is common to any individual who experiences the process of getting sick, and for the family. Note below:

"[...] This is a treatment that is going to cure me."
(Participant 11)

"[...] It's a good thing[...] It is a chance of cure."
(Participant 15)

"[...] it's a good thing for me [...]. I hope when I finish chemotherapy results will be normal." (Participant 16)

These statements represent adaptive responses to the situation in which treatment based on chemotherapy gave patients the opportunity to strengthen their mentality regarding the chance of a cure for cancer and the opportunity to have a normal life.

Chemotherapy, despite bringing the chance of being alive and resuming the daily life that has been altered from the diagnosis of cancer, promotes in the individual physical and psychological impacts resulting from its adverse reactions. Impacts that can be observed in the statements of six (27.2%) patients, in which they reveal that, although chemotherapy was identified as a chance for cure, it brought an additional meaning, of being a necessary evil, due to the adverse reactions. Note below:

"[...] It is a bad thing. When I was doing it, I felt sick, I couldn't eat, [...] I think this is the worst treatment I've ever done." (Participant 9)

"[...] For God's sake, I felt really sick, couldn't walk, in a wheelchair, I was weak, couldn't eat, couldn't eat using my own hands." (Participant 18)

"[...] Pain! It hurts, adverse reactions are very bad, hair loss, body ache, when I hear chemotherapy the first thing that comes to my mind is pain, but I tried to look on the bright side, it could cure me." (Participant 22)

It stands out in the testimonials of the patients, to view the treatment as something negative. This perception is due to the intensity of the adverse reactions they present, but it is also observed that despite the reactions, they considered continuing the treatment because they recognize that the side effects are not lasting and what is sought is the health recovery since cancer represents more danger than the treatment itself.¹

In this context it is evident the importance of a specialized professional, who can deal with the emotional processes that are triggered in oncological patients, being essential that he understands and provides emotional support to these transformations, as well as that he devotes time to listen to the patient, always keeping in mind that he is taking care of a human being and not only of the illness he brings.¹²

Therefore, it is the responsibility of health professionals, especially the nursing team, to help the patient and his/her family members to cope with the impact caused by chemotherapy, through its toxic side effects, as well as to provide information about the disease and the importance of continuing the treatment.

In this context, the Social Representations allow patients with cancer and in chemotherapy treatment the possibility of giving meaning to their experiences and their behavior, as well as the reality experienced and the world around them, through information that was built by themselves, from the need to adapt to their new reality.

Unit 2: Nursing care in chemotherapy

Care is known as the essence of nursing and can be divided basically into two types: professional care, which is performed by nursing professionals, and the non-professional, which is performed by family, friends and other individuals. It is established throughout the days, through the intersubjective encounters between the caregiver and the patient, in order to manifest their real meaning and new individualized ways of caring.¹¹

In this way, the nurse when caring for the cancer patient should be able to distinguish what is objective for him or herself and the real reality in which the cancer patients and their relatives live during chemotherapy. According to the testimonies of twelve (54.8%) interviewed, nursing care represents an attitude of occupation, concern and affective involvement with the other, in which the dispensing of attention to the patient and the behaviors performed by them is the main factor. Note below:

"[...] They take good care of us, they are attentive, taking care when it's over if we need something, they come." (Participant 3)

"[...] Nursing care, I think is very important for chemotherapy treatment. Due to the attention, she gives to the patient. They monitor us." (Participant 4)

"[...] Nursing care is essential. They are with us all the time. They are close, so I think nursing care very important for us, they support us." (Participant 16)

Thus, it is evident the need of the nursing team to keep up-to-date and qualified, to provide quality care to the cancer patient and his family, so that they can understand and support the patient in all his needs, especially in the chemotherapy treatment, as it is understood that the care provided by the health team should not only focus on the execution of techniques but also be expressed through acts and the relationship established with the patient.¹³

According to the testimony of another six (27.2%) interviewed, it was possible to observe a certain lack of knowledge about nursing care, which was related to medication administration only. Note below:

"[...] I don't know, they give us the medicine, the serum [...]." (Participant 2)

"[...] Nursing care is the way the nurse gives us the medicine correctly against the disease and taking care for the medication." (Participant 5)

"[...] I don't have any idea. They give us the medication." (Participant 12)

From these testimonies, it is possible to clearly notice the lack of knowledge about the essence of nursing care, which led the patients to report what they see in their daily lives with the nursing team, being, in this case, the medication administration. It is also evidenced in the testimony of the interviewee Participant 5 the concern about the knowledge and skills of the nursing team in the administration of chemotherapy.

In this way, it is fundamental that, in addition to their technical role related to drug handling, nurses act as multipliers of correct information regarding chemotherapy treatment, taking into account the physical and emotional upheavals caused by the aggressiveness of the treatment and the uncertain prognosis of cancer.¹¹

Four other (18%) interviewees associated nursing care with the provision of guidelines and information regarding the execution of their self-care. Note below:

"[...] The nurse gave me the guidelines to make everything right, and I see the care as a prevention for me, as feeding, use children shampoo, do not color the hair [...]" (Participant 19)

"[...] I imagine as a good thing, nursing care is the patient's well-being if the patient does not have those care, the nurse comes and teach him how to take self-care." (Participant 20)

"[...] Diets (laughs) for taking care of myself, take more care for my life, take care of myself." (Participant 9)

Through all of the above, it is observed that nursing care is understood as an authentic manifestation of the health service, even if there is a small part of the interviewees who understand such care as a mere execution of procedures and/or promotion of information. Thus in this unit, it was possible to perceive how the nursing care was inserted into the daily life of these patients and thus their social representations.

Unit 3: The every day of interpersonal relationships during chemotherapy treatment

Facing cancer is a difficult process for both the patient and his family, because despite advances in the oncology area, taboos, preconceived ideas and fears related to cancer are still common, concepts that permeate both patients and

people who live around them, in order to promote changes in the social relations maintained by the family.¹⁴⁻⁵

In this unit, all twenty-two (100%) interviewees reported that during the chemotherapy treatment against cancer they did not have much difficulty in maintaining their social relations, because they received the financial and emotional support they needed from their families and friends. Note below:

"Well, I didn't have many difficulties during the treatment, because my family supported me, my wife didn't abandon me, my children, friends I thought I didn't have [...] I found out that I have a lot of friends." (Participant 7)

"Thank God no one abandoned me, everybody helped me, financially and with love." (Participant 11)

"Thank God my family was very good to me, my friends, thank God, I never felt abandoned, neither from my family, or my friends, they were with me every time." (Participant 18)

However, three (13.64%) of these interviewees reported that their relatives only approached them with feelings of compassion and pity, being possible to observe in this testimony the presence of stigmas and negative taboos that the disease has. The also informed the non-acceptance of the self-image that was caused by the disease and its treatment. Note below:

"[...] They were close to me, because this is a serious disease [...] people feel sorry for you [...] I have a very close family, poor but close, thank God." (Participant 2)

"[...] Some people look at us with pity, we can see this because people look at us feeling sorry [...] they think we are dying, that life is over for us." (Participant 3)

"[...] I felt strange for being around them, I walked away, wanted to be isolated because I felt ashamed for being too thin, I was ashamed, they did everything for me, I wanted to be isolated, was ashamed for being thin." (Participant 8)

In family life, conflicts can be overcome, as long as everyone accepts and adapts to the new life situation, imposed by the circumstance of treatment. Family support, as well as friends and/or others influencing the patient's life, are essential for both treatment and rehabilitation.¹⁶ For this, it is necessary for the family member to seek the support of the other, Although it is difficult to witness the relative's fragility in the face of the disease and its treatment, face the

fear of the unknown, in order to offer at least the stimulus that his loved one needs.^{14,16-7}

In this context, the nurse's role is indispensable, in order to promote the understanding of these individuals about the disease and its treatment, so that it comes through a therapeutic communication to facilitate the coping of the disease and its treatment, as well as to strengthen the nurse-patient-family bond.⁵

Regarding the family and patient relationship in antineoplastic chemotherapy, the importance of family valorization and the family incentive to participate in the care of its sick member is emphasized, in order to promote a more effective care and in which the patient can face treatment more easily, considering that the family is the main social institution in which the individual initiates his/her affective relationships, creates bonds and internalizes values.

Unit 4: Difficulties during chemotherapy treatment

Several factors may interfere with the continuity of an antineoplastic chemotherapy treatment, the most common being the treatment side effects, the financial situation, the distance for the place of treatment and the lack of knowledge about the importance of chemotherapy for cancer.¹⁶

According to the testimonies of twelve (54.54%) patients, the main difficulty they encountered during chemotherapy was the treatment side effects, demonstrating that their perceptions about chemotherapy turned only to the unpleasant treatment consequences. Note below:

"[...] Well, the chemotherapy difficulties was the medicine that we took, felt sick, couldn't sleep, dizziness, weakness, bad things that I still feel nowadays." (Participant 12)

"[...] They are only about the bad reactions of chemotherapy [...] makes us feel sick, diarrhea, vomiting, lately it is making me angry [pause] and I get angry." (Participant 13)

"[...] The difficulty was that I couldn't walk and feed myself." (Participant 17)

According to the testimonies, it can be observed that the chemotherapy side effects are presented in a unique way for each patient, some with more harmful potential such as "not walking" and others with a lower degree of aggression such as "nausea, weakness, and diarrhea".

According to the authors, the main symptoms resulting from chemotherapy and that affect patient's body image are alopecia, pain, nausea, vomiting, diarrhea, mucositis, phlebitis, and fatigue.^{6,18} Such reactions during the treatment result in changes in appearance Physical, in the abilities and performance of the patients' daily functions, and could have

a negative repercussion on this patient's life, as evidenced by the speech of the participant patient 13, who reported feeling angry.

The importance of nurses in the orientation of these patients and their families is emphasized, especially during the nursing visit, in which time should be given to listen to the patient and his family, undo their doubts, explain the side effects and the particularities of chemotherapy treatment, because the more informed the patient and his family are about the side effects of chemotherapy and how to control them, the better they can coexist and deal with it.^{1,5}

Difficulties such as the shift to the institution, the consequent routine alteration, and the financial situation, were also pointed out by ten (45.46%) interviewed as difficult factors imposed on them by the treatment. Note below:

"[...] The problem is that I depend on money and I live far from the hospital, the transportation issue." (Participant 21)

"[...] The difficulty is the transportation because we live far from the hospital, and we have to pay for it [...] because we stay here for long and our salary is low, this is the difficulty." (Participant 16)

"[...] The difficulty is the journey, it is a routine, come here every day, I paid a driver to bring me, I felt sick." (Participant 9)

The financial difficulty reported by the patients is justified by the fact that, in most cases, the member affected by cancer was considered to be the housing provider through their services provided to society and which were impaired for the accomplishment of the chemotherapeutic treatment, as well as the family service that is available to accompany you in the treatment and so be with your loved one.

Faced with these changes, patients experience some stages of denial until the acceptance of the disease and adherence to the treatment, which is part of the process of coping with the disease and resilience. This knowledge on the part of health professionals enables them to develop actions that involve health education, in addition to influencing the level of adherence to treatment, so that each positive factor involved in the rehabilitation process becomes an intervention target for the multi-professional team.¹⁶

In this context, it is clear the need for actions aimed at the support and guidance of family members and patients with cancer in all its aspects, in order to enhance their quality of life, maintain their autonomy and capacity for self-care, as well as their family and social life.

CONCLUSION

In this work, we sought to know the social representations of cancer patients on chemotherapy treatment and nursing care. The treatment is represented as a chance of cure, in which, if it is necessary, you endure such evils as the adverse reactions in order to achieve the longed for good. Regarding nursing care, it was represented as an attitude of occupation, concern and affective involvement with the other, as well as the execution of technical care in the drug administration and manipulation used in the treatment and distribution of information regarding the patient self-care.

Through all of the above, it was evidenced the importance of nursing throughout the chemotherapy treatment process, since it is the category that is in the continuous follow-up of the patient and that tends to provide guidelines on the chemotherapy treatment for the patients involved. Such guidance is fundamental for the understanding of these patients and their families, as it may undo taboos and provide better adherence to chemotherapy treatment and coping with the disease.

For the people interviewed, guidance and clarification of doubts about the disease and its treatment, in a patient and caring way, were considered fundamental elements to help them and to promote them comfort during the course of chemotherapy. Such information can be passed on through discussion groups, informational folders and even through bedside conversations with patients and their families. During the process of health and illness, people often need to feel protected, secure, oriented and know that they can count on someone to share their experience and clear their doubts.

Thus, nursing must make the discourse on care to the essence of its actions with the other. Caring is to have as a goal the recovery, prevention, maintenance and promotion of the individual's health in its integrality and singularity. The essence of nursing is care, which is the true instrument of nursing professionals, which goes beyond the execution of techniques and reaches the institution of trust and empathy with the patient.

In this sense, in order to take care of oneself, it is necessary, at many moments, to put oneself in the place of the other and to perceive, even in nonverbal language, the physiological and emotional needs, providing the other comfort and security, so that he/she can live better with the difficult times, in a more pleasant and quiet way.

Thus, the research revealed the importance and the contribution of knowing the representations of these patients with regard to the chemotherapy treatment and the importance of the nurse's performance with the patient in antineoplastic chemotherapy.

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